



# YOUTH ARE EXPERTS TOO.

Strategies to Engage Young Adults in the Research Process

## Community engagement is fundamental to HIV research.

One of the first examples of community involvement in HIV research began with the first federally funded and mandated community advisory boards (CABs) in 1989. Since then, CABs have become a regular feature for most clinical trial networks seeking to improve the effectiveness and ethics of research.

However, the effectiveness of community involvement in research may still be limited by insufficient resources, training, or political forces necessary to make CABs and community-engaged methods more than just “a box to be checked.” It is essential for the field of HIV research to challenge norms and barriers for community engagement to live up to ethical obligations set forth by academic institutions and to effectively address the systemic inequities that dictate our research priorities and, more importantly, define the daily lives of the communities we serve.

## Gaps remain when it comes to how community members are folded into the research process.

A 2018 review of stakeholder engagement in HIV clinical trials found that most studies engaged stakeholders to develop protocols (45%) and recruit participants (44%), and less often to:

**14%** generate research protocols

**23%** analyze and interpret Data

**10%** disseminate findings.

Stakeholder engagement is also mostly conducted using researcher-driven, top-down methods such as interviews or focus groups (30-40%).

Source: Day, S., Blumberg, M., et al. (2018)

## Youth Engagement in the ATN

As the only U.S. research network solely focused on addressing HIV among youth, the Adolescent Medicine Trials Network for HIV Interventions (ATN) seeks to better center youth engagement in the research process. Youth engagement allows researchers to gain relevant insights into how youth engage with services, create relevant and responsive interventions, and improve the accessibility of said services or interventions.

In 2021, the ATN merged and re-branded Youth Advisory Boards and the Youth Advisory Council from the ATN's iTech network into a single entity to recognize the need for youth engagement through all parts of the research process. Members were formally hired as part-time university employees in a research consultant role to better respond to evolving study needs, while also being able to offer them additional resources and professional development opportunities. This group has continued into the present iteration of the ATN under a new, self-determined name: Subject Matter Research Consultants, (SRMCs)

## Why this document?

The purpose of this document is to provide tips and tools to help researchers prepare for meeting with SMRCs. So as you read through this document, we encourage you to reflect expansively:

*How can the ATN continue our field's tradition of re-defining the relationships between researchers and community to improve equity and impact?*

## Everyone benefits from researcher-youth partnerships.

A 2022 review of youth engagement in research found several personal benefits for both researchers and youth.

### Youth reported:

- Feeling empowered
- Gaining new skills and knowledge
- Better career and learning opportunities
- Broadening their support networks

### Researchers reported:

- Increased accountability
- Enhanced understanding of findings
- Gaining appreciation for engagement
- Pride in youth's professional and personal development

Source: McCabe, E., Abarbayan, M., et al. (2023)



# Before a meeting

Research environments often present challenges to communicating information in ways that are not only digestible but also accessible for youth who might:

- Be unfamiliar with academic terminology or concepts
- Prefer more engaging forms of communication, like infographics or video
- Have goals and expectations distinct from the project.

One way that researchers can support youth as informed partners in the research process is by taking the time to adequately prepare before meeting with youth. Whether a researcher is looking to review recruitment materials or gather input for their intervention's design, the following strategies and questions are just a few ways researchers can facilitate improved capacity for engagement, collaboration, and questioning among youth partners in the research process.

## #1

### Clearly outline your study and why you're there.

Review the questions below to make sure you are prepared to present or answer questions related to different aspects of your research study.



### How does participating in this project support my goals?

Youth deserve the opportunity to accurately understand a study and how it relates to their own interests, goals, and communities.

#### Study Basics

- What is your research study trying to do? Why?
- What is the intervention?
- How is this intervention different from similar strategies?
- What type of data do you want to collect?
- Who are you recruiting, and where?

#### Importance

- What is the context for your study as it relates to health, policy, service-delivery, and related research?
- Why should lay constituents care? How will your study affect the daily lives of youth or people serving youth?

#### Challenges

- What issue or challenge do you seek to address with youth?
- What, if any, solutions have you already considered?
- What constraints or limitations does your team face for initial and/or additional solutions?
- What questions or asks do you have for youth?



## Promoting constituency among young stakeholders

One of the burdens of involving youth in research is the tendency to ask one or a very small number of young people to represent the youth perspective as a whole, something that often happens when a young person is invited to sit on advisory committees. This burden should be challenged by giving young people the time and resources to build their representative voice and practice good constituency.

Constituency refers to the process of gathering ideas and perspectives from peers or people one represents. Youth can practice thinking about constituency by tackling activities, like the examples on the right, to encourage youth to think about the similarities and differences between their own experiences and the experiences of those around them.

## #2

### Get creative and engage youth before meeting.

Pre-meeting activities can help youth feel more prepared to discuss your study and asks. They can also enrich feedback from youth, especially if you're soliciting opinions that "represent" youth.

**Send 2-3 teaser questions generally related to your issue .**

*Example: What do you know about the presence of methamphetamine among queer youth?*

**Ask youth to collect specific information beforehand.**

*Example: If you need feedback on app features that appeal to youth, ask the SMRCs to make a list of 3 to 4 apps that they enjoy using in their day-to-day life and what they like about them*

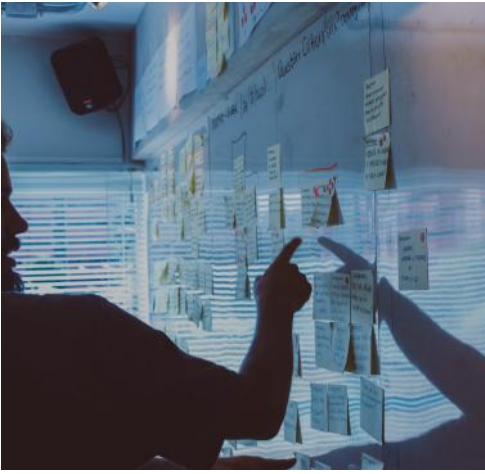
**Provide resources to learn more about a project, issue, a subject ahead of time, such as:**

*Examples: current events articles, videos about app design, webinars, and journal articles*

## #3

### Check-in with the adult-youth liaison.

Beyond just adding your project to an agenda, the liaison can help review the appropriateness of content and provide additional ideas or feedback on how to engage SMRCs effectively.



## During a meeting

Structured institutions are not usually designed to support a partnership approach when working with youth, and require an active effort from researchers and other adult leaders to curate spaces and opportunities so young adults can feel validated and empowered to engagement. The following suggestions are a few of the ways researchers can run meetings to increase equitable participation:

### #4

#### Creating a safer environments

Check-in with your team and set ground rules to make sure that youth feel respected and valued. Examples of ground rules include:

- Sticking to the pre-established agenda so everyone is on the same page.
- Having one speaker at a time and avoiding side conversations.
- Talking directly to youth with concise, lay language.
- Practice active listening.
- Respecting pronouns and/or lived names.
- Avoiding language that can perpetuate harm or stereotypes (e.g., "risky" behavior).

For additional reading on harmful language, see:

- ["Facing HIV Stigma in Our Own Words,"](#) article on people-first language .
- [NIAID Language Guide,](#) document on best practices around sexuality, race, and other identities.



**Young people will think what we're asking them to do is too boring or not important.**

#### **Check your adultism.**

Adultism is a form of ageism that refers to behaviors or beliefs that adults have more value or potential contributions than children and young adults. Adultism is a serious roadblock for researcher-youth partnerships, assuming the superiority of adults and supports the belief that youth need to become adults before they can contribute meaningfully. It can create a bitter, stressful, non-productive and even destructive atmosphere.

#### **Researchers can step up to the plate as adult allies by:**

- Acknowledging any biases that they might have coming into a partnership
- Supporting youth to have ownership of a project and get creative
- Not imposing judgments or ideas
- being willing to take risks
- Sharing power and accountability for successes and failures

## #5

### **Diversify strategies for discussion.**

Youth might not feel immediately comfortable speaking up in a traditional discussion setting with researchers and other adults, especially if the topic is new or complicated. Structure discussion in ways that provide multiple opportunities to express ideas, offer comments, or share feedback.

- Taking a moment to write down responses and then share them as a group.
- Asking to share written feedback via chat, email, or a survey.
- Using interactive Zoom features like polling.
- Checking in for understanding and clarifications from time to time.

## #6

### **Be inquisitive rather than making statements.**

A question that might be simple to researchers might be too specific or challenging for youth, who might need more time to process the information and reflect before responding. Approach the discussion from a different angle using questions that are low-stake yet demonstrate a genuine curiosity in their thoughts and opinions.

- What surprised you most?
- What is the most important thing you learned?
- What is the most interesting thing you learned?
- What do we think others should know about this issue?
- What should we spend more time learning?
- What do you want to do about this issue now that you have learned more?

## #7

### **Ensure that youth can have an impact on decision-making.**

Research teams do not have to plan entirely around youth feedback, but team members should demonstrate an active effort to incorporate youth's interests, feedback, and contribution into key discussions and decisions.

- Openly discuss everyone's goals and incorporate youth's goals into your team plan. What brings youth to the table? How can you support their goals and interests?
- Avoid coming in with predetermined solutions before you have a chance to collaborate with youth.
- Check assumptions about youth's interests and ability to contribute to decision making.





## The importance of being culturally humble.

Cultural humility refers to the lifelong process of self-reflection, self-critique and commitment to understanding and respecting different points of view, and engaging with others authentically and from a place of learning. Research on cultural humility shows their importance in fostering trusting relationships with youth and fostering youth's identity development.

Ways to build cultural humility with youth:

- Build an understanding of young people's experiences.
- Exercise self-reflection and explore feelings that come up.
- Recognize your own and other's power and privilege.
- Build your comfort with not knowing and open the door to learning.
- Adapt the existing culture and co-create new traditions with youth.

For further reading on cultural humility and mentorship, [see this resource](#).

## #8

### Be transparent about your decision making.

One of the best ways to demonstrate that youth are a valuable part of the decision-making process is practicing transparency. Transparency is demonstrated when motives, methods, and limitations are clearly and openly communicated.

#### Explain the reasoning behind a decision or process.

How will your group come to a consensus? What are the barriers or constraints that you operate under?

#### Address mistakes or areas for improvement.

What factors contributed to a mistake? What specific steps will you take to address a problem?

#### Provide honest feedback on youth input.

How do you plan to incorporate their input? If something cannot be implemented, don't shy away from explaining why.

#### Review decisions and next steps as a group.

If you've assigned youth a follow-up task, check-in to see if they need any additional support, such as a one-on-one meeting to review the task.

## After a meeting

Part of moving away from asymmetrical and extractive models of community partners is honoring a relationship beyond its function for a specific event, meeting, or project. Researchers should plan to incorporate sustainability practices and spaces to maintain relationships, motivation, and action with youth.

By taking the time to follow-up with youth after a meeting or share exciting opportunities in the future, researchers can demonstrate to youth that their contributions are not only valued within the scope of their project but also as individuals with full lives – be it goals for attending medical school, active projects in their communities, or simply expanding their horizons.



## #9

### Report back in a timely manner.

Hearing about the impact of their contribution can motivate youth to stay engaged and manage expectations for future involvement, even in cases where their input was not used.

- How has youth input changed the way you thought about different parts of your project?
- Have you gotten additional community input since your discussions with youth?
- Have you made changes to the materials/intervention in language or design?
- What barriers or challenges prevented you from fully implementing youth recommendations?

## #10

### Share other opportunities.

Youth's support network should expand, not shrink, following a youth engagement activity.

- Involve youth in dissemination activities, such as developing social media content of your findings.
- Invite youth to collaborate on other projects you're a part of.
- Share more learning opportunities like conferences, workshops, and community forums.

## #11

### Work towards co-authorship.

Researchers need to continue collaboration with youth throughout the entire research process, especially when it comes to writing for peer-reviewed journals. Involving youth in this process not only ensures that researchers incorporate their perspectives into the manuscript, but also builds up their experience and capacity in academic settings.

- What is the process for developing a potential article? Who needs to be involved?
- What are the criteria for authorship? How will you factor in different levels of experience, interests or capacity for writing?
- What will the writing process look like? How often will co-authors meet to review writing?
- Should a parallel document be created that summarizes findings for lay audiences?

For additional resources on coauthorship and crediting youth see:

- [Authorship determination scorecard](#)
- [General guidelines for authorship](#)
- [Authorship practices for community-engaged research](#)



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To learn more about the ATN visit: [www.atnconnect.org/](http://www.atnconnect.org/)

